

ALABAMA INTERAGENCY AUTISM COORDINATING COUNCIL



Fiscal
Year
2017-
2018

Annual Report

Autism Spectrum Disorder (ASD) is a developmental disability that causes substantial impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASD have unusual ways of learning, paying attention, and reacting to different sensations. The thinking and learning abilities of people with ASD can vary from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout the life of a person with the disorder. (Act 2009-295)

The Alabama Interagency Autism Coordinating Council, created by the Alabama Autism Support Act of 2009 (Act #2009-295), is charged with meeting the urgent and substantial need to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system of care (SOC) for individuals with Autism Spectrum Disorder (ASD) and their families.

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Foreword: Autism in Alabama

The Alabama Interagency Autism Coordinating Council (AIACC) 2018 *Annual Report* provides updates on progress toward achieving goals set out in our charge, mission, and 2014-2017 *AIACC Strategic Plan* during Fiscal Year 2017-2018 (FY2017).

The Centers for Disease Control and Prevention recently released new findings that showed a prevalence rate for ASD to be 1 in 59 (previously 1 in 68). Nearly one-third of those children with ASD had a co-occurring intellectual disability. Only forty-two percent of children identified with ASD were evaluated for developmental concerns by age three, when ASD can be diagnosed as early as two years of age.¹

The national perspective and standard of care related to services for those with developmental and intellectual disabilities has evolved over the past few years. The Workforce Innovation Opportunity Act (WIOA) and the Home and Community Based Settings rule change are only two examples of federal changes with broad reaching impacts. According to the Department of Labor, “WIOA is landmark legislation that is designed to strengthen and improve our nation's public workforce system and help get Americans, including youth and those with significant barriers to employment, into high-quality jobs and careers and help employers hire and retain skilled workers.”² Alabama's ongoing implementation of WIOA allows for greater access to resources and supports for youth and adults as they gain life and employment skills. The Home and Community Based Settings rule highlights a person's independence, personal choice and rights, and integration in the community. As state agencies continue to adapt to the new rules and legislation, opportunity to access services has expanded. Focus on the individual has become greater and more thoughtful, as better individual outcomes are sought.

Changes within our state have also impacted access to services. Alabama became the 46th state to require insurance coverage for Applied Behavior Analysis (ABA) therapy in 2017. We have seen the early stages of implementation of coverage this fiscal year, and looking back, have seen the initial impacts. While providers begin to enroll and file claims, we have quickly found that provider capacity and enrollment in coverage continues to be a need. Previous unavailability of reimbursement options beyond private pay led many providers to move out of state. In addition to private insurance companies, the State Employee Health Insurance Plan, the Public Education Employee Insurance Plan, ALL Kids, and Alabama Medicaid were required to cover ABA therapy. Access to ABA coverage can change the quality of life and future outcomes for people with autism, as well as their families. This legislation was a huge step forward for Alabama.

The Alabama Regional Autism Network (RAN) was funded in FY2016 after authorizing legislation was passed in 2009 allowing for creation of the RAN. In the first year of the RAN's existence, over 2,500 people were served through individual and family assistance, consultation and technical assistance, professional training, and public education. In FY2017, two more RAN sites were added with the support of increased funding, allowing the RAN to have statewide impact. During FY2017, 4,632 individuals were served. We expect the breadth and scope of the impact of RAN to continue to grow with each year. People with ASD, their families, service providers, and educators can call these university-based RAN sites, talk with experts in the field of ASD, and connect with the information or service they need.

¹ CDC's ADDM Network data, <https://www.cdc.gov/ncbddd/autism/addm.html>

² U.S. Department of Labor, <https://www.doleta.gov/wioa/>

While these changes have had positive impacts in our state, access to services continues to be a major barrier, particularly for youth and adults. While we know that early intervention has great effects, some youth or adults may not have had an opportunity to benefit from the services just now becoming available. Also, many children will need continued support and intervention when they become adults. Currently, most adults with ASD do not meet eligibility criteria to receive supports for home and community based living. Families remain at a loss when it comes to care for their adult child or children when they need intensive supports, as Alabama does not allocate resources to provide this for those affected by ASD without an intellectual disability, beyond employment and educational support.³

The following are highlighted identified needs that affect those with Autism Spectrum Disorder in Alabama:

- **Prioritize transition and adult services.** A large number of youth with ASD are entering adulthood. They need services to improve this transition into adulthood and supports to help them maintain the maximum amount of independence once they reach adulthood.
- **Expand funding for all Regional Autism Networks.** In 2017, all five Regional Autism Networks (RANs) were funded at \$75,000 per site. The RAN sites are Auburn University, University of Alabama, University of Alabama at Birmingham, University of Alabama in Huntsville, and University of South Alabama. To ensure a full-time, dedicated staff member and funding to carry out their duties as the demand for services grows, each RAN site needs increased funding. Act 2009-592 allowed for the creation of Regional Autism Networks when funding was made available through the Legislature. Individual and family assistance, as well as training, technical assistance and consultation for service professionals and educators would build capacity and contribute to the needed resources and fill the gaps for those with ASD.
- **Expand waivers to include developmental disabilities.** Alabama is one of three states that does not include Developmental Disabilities (DD) as a qualifying condition to receive specified waiver services. The current CDC prevalence study found that only 31% of those identified with ASD had a co-occurring intellectual disability (which is required for access to waiver services). This is a gap in care that tremendously impacts people with ASD in Alabama.
- **Encourage recruitment and retention of Board Certified Behavior Analysts (BCBAs) in Alabama.** Access to ABA therapy allows for opportunity to grow the capacity of the workforce of BCBAs, Board Certified Assistant Behavior Analysts (BCaBAs), and Registered Behavior Technicians (RBTs). Supporting current and developing training programs in the state, as well as offering scholarships and stipends with the requirement that the student must return the investment by staying in state for a certain number of years is recommended for the growth of workforce and access to services.
- **Continued expansion of insurance coverage for ASD Services, including Applied Behavior Analysis and other evidence based therapies.** While many private insurance plans were required to include coverage for ASD Services, including ABA, other plans were not impacted by the legislation. Public coverage of services was also made available during the 2017 legislative session.⁴ Expanded private coverage options are crucial for the wellbeing of people with ASD and their families in Alabama.

⁴ In Alabama, 41% of all children are covered by Medicaid or ALL Kids. (https://www.aap.org/en-us/Documents/ccs_factsheet_alabama.pdf).

About the AIACC

HISTORY

Alabama Autism Task Force

On March 20, 2007, Representative Cam Ward and Lieutenant Governor Jim Folsom, Jr. announced the formation of the Alabama Autism Task Force (AATF). House Joint Resolution 23 was passed by the Alabama Legislature on March 8, 2007 and signed into law by Governor Bob Riley shortly afterwards. The AATF reviewed the state's response to the increased incidence of ASD.

The AATF was comprised of advocates, state officials, educators, physicians, and members of the academic community to recommend ways to improve the treatment of autism in Alabama. Representative Ward and Lt. Governor Folsom served as Chairmen for the AATF, which held its first meeting on June 17, 2008. The final meeting of the AATF was held on January 22, 2009.

The AATF was composed of 27 appointed members and a number of volunteers, and was organized into the following Subcommittees: Diagnosis and Early Screening, Intervention Services (0-5), Intervention Services (6-21), Intervention Services (Adult), Health Care, Ad Hoc (Regional Network Development), Systems of Care, and Financial Impact.

Each Subcommittee reviewed data gathered through the Alabama Autism Needs Assessment, which was conducted in conjunction with the AATF's activities. Recommendations were given based on current identified needs and available research.⁵

Alabama Autism Collaborative Group

The Alabama Autism Collaborative Group (AACG) received a grant from the Alabama Council for Developmental Disabilities (ACDD) to conduct a statewide Autism Needs Assessment in order to guide the recommendations of the AATF. The AACG conducted a thorough literature review to determine current best practices, seven community and family forums, in person and online surveys of parents and service providers, and key informant interviews. The Needs Assessment was conducted between September 2007 and May 2008.⁶

Alabama Interagency Autism Coordinating Council

The AIACC was created to carry out the work of the AATF once it dissolved in 2009. The AIACC, secured by the Alabama Autism Support Act of 2009 (Act #2009-295), is charged with meeting the urgent and substantial need to develop a statewide, comprehensive, coordinated, multidisciplinary, interagency system of care (SOC) for individuals with Autism Spectrum Disorder (ASD) and their families.⁷

⁵ Alabama Autism Task Force: Final Report to the Governor and Legislature, January 2009, http://autism.alabama.gov/Documents/Autism_Task_Force_Final_Report.pdf

⁶ Statewide Autism Needs Assessment: Final Report, June 2008, Alabama Autism Collaborative Group, http://autism.alabama.gov/Documents/Autism_Needs_%20Assessment_Full_Report.pdf

⁷ Alabama Autism Support Act (Act 2009-295), http://autism.alabama.gov/Documents/Legislation/ACT_num_09-0295_HB0041.pdf

Recommendations from the AIACC are to be derived from scientifically based research and nationally recognized best practices. The AIACC is also to ensure interagency collaboration, public participation, and mutual sharing of information to facilitate policy decisions and the implementation of a plan for a comprehensive statewide system of care to individuals with ASD.

The AIACC is to develop a long-term plan and steps toward creation and implementation of a comprehensive system of care. The plan is to address: identification barriers such as duplicative or fragmented policies which may require modification; the development of a coordinated program of services; a comprehensive fiscal review, analysis and recommendations for state spending on programs and services for ASD; and the identification of annual action steps toward implementation.

MEMBERSHIP

The AIACC is composed of the following members:

Governor appointed members include⁸:

Brooke Bowles
Robert Caldwell
Greg Carlson, Co-Chair
Lucian Cronkite
Sally Davis

Suzanne Dowling
Megan Everett
Joshua Heard
Doris Hill, Ph.D.
Whitney Meade, Ph.D.

Sarah Ryan, Ph.D.
Todd Tomerlin
Karen Willis

Senate Appointee: Cam Ward, Chair

House Appointee: Becky Nordgren

The chief executive officer or a representative from each of the following state agencies:

Alabama Council on Developmental Disabilities
Alabama Department of Early Childhood Education
Alabama Department of Education
Alabama Department of Human Resources
Alabama Department of Insurance
Alabama Department of Mental Health⁹
Alabama Department of Public Health
Alabama Department of Rehabilitation Services
Alabama Institute for Deaf and Blind
Alabama Medicaid Agency
American Academy of Pediatrics – Alabama Chapter
Autism Society of Alabama
University Center of Excellence in Developmental Disabilities Education, Research, and Service

⁸ Governor appointed membership includes: three adults with ASD, three parents of children with ASD, one parent of an adult with ASD, five service providers, and one health insurance representative.

⁹ The Alabama Department of Mental Health is the lead agency for the AIACC.

Year in Review

LEGISLATIVE REVIEW

Relevant Legislation

Senate Bill 381 allowed for the creation and purchase of a “person with autism” license plate for those individuals with ASD who had an ASD identification card or their guardian.

House Bill 284 (Act 2017-337), from the 2017 legislative session was enacted on October 1, 2017, requiring coverage of screening, diagnosis, and treatment, including ABA therapy, for children aged 18 years and younger in policies with 51 or more employees (by October 1, 2017), the Public Education Employee Health Insurance Plan, the State Employee Health Insurance Plan, ALL Kids, and Alabama Medicaid (all by December 31, 2018).

Budget

Total state dollars allocated to support the mission and recommendations of the AIACC in FY2017 was \$498,900. Funding is allocated in both the State General Fund (\$60,000) and the Education Trust Fund (\$438,900).

In the Education Trust Fund (ETF) for FY2017, the AIACC was allocated \$438,900. This expanded the Regional Autism Network (RAN) sites to five (previously three), thereby having a statewide scope. Each of the five RAN sites are allocated \$75,000. The university RAN sites include: Auburn University, University of Alabama, University of Alabama at Birmingham, University of Alabama in Huntsville, and University of South Alabama. Also related to Autism Services, a total of \$3,250,000 new funds was appropriated in the ETF for “services for children and youth with severe emotional disturbances and medically necessary services for Medicaid eligible children with autism spectrum disorder.”

GENERAL UPDATES

The Regional Autism Network (RAN) began its second year and added two universities, becoming a statewide entity. The currently designated RANs are housed at Auburn University (AU), University of Alabama (UA), University of Alabama at Birmingham (UAB), University of Alabama in Huntsville (UAH), and University of South Alabama (USA), and each site was awarded \$75,000. AU, UAB, and USA were awarded funds in 2016, which UA and UAH were added to the Regional Autism Network in 2017. During the last fiscal year, RANs have reached over 4,500 people with information on ASD, resources, and training (RAN reached 2,500 people during its inaugural year). Each Regional Autism Network provides: 1) staff with expertise in Autism Spectrum Disorder; 2) individual and direct family assistance in the home, community, and school; 3) technical assistance and consultation services; 4) professional training programs; and 5) public education programs. These activities provide training and support to new and existing service providers and to individuals with ASD and their families. A strong relationship with Alabama’s universities allows for greater access for families and service providers to training opportunities and resources. The relationship of the university to the community has grown tremendously, and it is expected to continue to grow with the continuation of the Regional Autism Network. (See Appendix A for RAN Legislation and Appendix B for RAN Mission, Vision, and Values).

<u>Type of Service Provided</u>	<u>Auburn University</u>	<u>University of Alabama</u>	<u>University of Alabama at Birmingham</u>	<u>University of Alabama in Huntsville</u>	<u>University of South Alabama</u>	TOTAL
Direct Assistance to families affected by ASD	163	68	69	5	219	524
Technical Assistance and Consultation	85	23	24	1	52	185
Professional Training	363	340	635	331	389	2058
Public Education	888	412	462	12	91	1865
TOTAL	1499	843	1190	349	751	4632

For October 1, 2017 – September 30, 2018

Regional Autism Assessment work completed in 2016 and 2017 has greatly informed the work of the RAN sites. Families and service providers are more easily connected with existing resources. The listing of resources continues to grow as the RAN sites reach the broader community.

The AIACC is working with UAB's School of Public Health to update the current Strategic Plan, as well as on an Environmental Scan and Rapid Needs Assessment. The work is expected to be completed in October 2018.

The AIACC Executive Committee will meet in early 2018 to discuss upcoming changes to autism services in Alabama as a result of 2017 legislation.

The need for transition (youth preparing for adulthood) and adult services has been voiced strongly in a variety of ways (during AIACC meetings, surveys in planning for Regional Autism Network activities, and national data). Preliminary data from the Rapid Needs Assessment and Environmental Scan supports this identified need as well.

STRATEGIC PLAN

The AIACC completed work on the 2014-2017 Strategic Plan. See Appendix C for full plan progress and activities. The AIACC is working with UAB's School of Public Health in 2017-2018 to update the current Strategic Plan, which is anticipated to be completed in late fall 2018. The targeted goals/committees for 2014-2017 were:

Accountability: To promote evidence-based, high quality, cost effective models and best practices that provide supports to persons with ASD and their families.

Public Awareness: To raise public awareness of issues and needs affecting persons with ASD and their families.

Funding: To identify and promote opportunities for diversified public and private partnerships that expand needed funding.

Accessibility: To advocate for increased choice among and access to quality services and supports for people with ASD and their families.

Regional Networks: To develop and coordinate necessary resources that allow for the creation of Regional Networks (through Act 2009-592, see Appendix A).

BARRIERS

People with ASD face many barriers. Families in Alabama quickly find out that a diagnosis of autism does not necessarily qualify a person for services or coverage for services. The only state agencies that include ASD as an eligible primary diagnosis for services is the Alabama State Department of Education (ALSDE) and the Alabama Department of Rehabilitation Services – Early Intervention (EI) program; however, by the time a diagnosis is made, most children are older than age 3, which is the cutoff of the EI program's eligibility. Often, several medically necessary therapies are prescribed by a diagnosing physician and/or team, and these therapies are typically not available through ALSDE or EI in the dosage prescribed, nor are those agencies structured or intended to provide all the prescribed therapies.

For people with ASD to access needed services beyond what is offered by state agencies (other state agencies may offer services to individuals with ASD, but this is not based on their ASD diagnosis, but rather other eligibility criteria), private or public insurance and private funds are needed. While much progress has been made in including ASD services in health policies, more work is needed to ensure access for all families in Alabama.

Due to the many reimbursement issues in Alabama for ASD services and the resulting loss of Alabama-trained providers to neighboring states, there are fewer diagnosticians and treatment providers in Alabama. Waiting lists can be as long as a year or more to receive a diagnostic evaluation (or longer for older children), especially for those with Medicaid. In a largely rural state, most ASD providers are in Alabama's urban centers, namely Birmingham, Huntsville, Mobile, Montgomery, and Tuscaloosa. Although services exist in other cities as well, the number of providers is very few if they exist at all. More insurance coverage to reimburse and keep providers in our state is necessary to meet the demand for necessary and timely services. Incentives and training opportunities might also assist in attracting and keeping service providers in our state after they graduate.

Since ASD is not a qualifying condition for many publicly funded services in Alabama, it is not tracked in those systems. Typically, only the primary diagnosis (qualifying condition) is tracked, so if those being served happen to also have ASD, there is currently no way to count them. We need to know how many people with ASD are currently being served under other eligibility criteria, and we need to have appropriate services to match the needs specific to ASD.

The Regional Autism Network has grown exponentially in reach and offerings for their region. Currently, funding levels only allow for a half time staff member at each region. While we are pursuing alternate options for funding, expanded legislative funding would allow for a much greater impact. With many changes in the state in regard to ASD, the RANs play a key role in training and connecting families and providers to the services and information in their area.

The AIACC hopes that progress can be made during the next fiscal year on removing some of these persistent and problematic barriers.

Conclusion

This past year was a landmark time for families in Alabama as they celebrated expanded coverage through HB284, which made ASD coverage, especially ABA therapy, available to so many populations. As the coverage comes available, there will be continued issues to work through, but the AIACC is encouraged by the great progress accomplished. More work is left to be done. The expansion and continued growth of the Regional Autism Network has proven even more important as families seek to access these newly available services, and as educators and service providers need help navigating and serving people with ASD.

Many of the identified barriers are being addressed at the state and legislative levels and it is anticipated that responses and answers to these issues will be made available in the coming fiscal year. With the start of the Regional Autism Networks in Alabama, and anticipated expansion to statewide reach, a greater opportunity to connect families to services and train communities on best practices will continue to move forward the goals of the AIACC in developing a coordinated system of care for those with ASD. The AIACC has made significant steps toward crafting a System of Care that will benefit individuals affected by ASD and their families, as well as those providing services. While there is much left to be done, the cooperation among agencies and individuals has made the process more efficient. Obtaining funding for Autism Regional Networks and updating the Strategic Plan through data gleaned from the Rapid Autism Needs Assessment and Environmental Scan are priority activities for the AIACC.

Regional Autism Network Legislation

APPENDIX A

The establishment of the Regional Autism Networks (RAN) (Act 2009-592) is a critical element of the statewide system of care. The legislation outlines the basic requirements of the networks. It is the hope of the AIACC to see five networks strategically placed around the state. The use of the term “Network” was agreed upon by the AIACC to emphasize the regional capabilities regarding expertise and sharing of information. Three RANs were established in 2016, with the hope and expectation that the remaining two will be funded in 2017.

REGIONAL AUTISM NETWORK LEGISLATION (ACT 2009-592)

Establishment of regional autism centers; constituency board; rules and regulations.

(a)(1) There is established in determined geographic regions of the state one or more autism centers whose purpose is to provide nonresidential resource and training services for persons of all ages and of all levels of intellectual functioning who have any of the following:

- a. Autism.
- b. A pervasive developmental disorder that is not otherwise specified.
- c. As determined by the Alabama Interagency Autism Coordinating Council, other disability populations which may receive benefit from the services and activities of the regional centers.

(2) Each center shall be operationally and fiscally independent, and provide evidence-based services within its geographical region of the state. Service delivery shall be consistent for all centers. Each center shall coordinate services within and between state and local agencies and school districts but may not duplicate services provided by those agencies or school districts. The respective locations and service areas of the centers shall be recommended by the Alabama Interagency Autism Coordinating Council and selected by the Governor, the Lieutenant Governor, and Speaker of the House of Representatives.

(b)(1) There is established for each center a constituency board, which shall work collaboratively with the center. Each board shall consist of no fewer than six members, each of whom is either an individual who is, or a member of a family that includes, a person who has a disability that is described in subsection (a).

(2)a. The Governor, the Lieutenant Governor, and Speaker of the House of Representatives shall select the members for the board from a list that has been developed by the Alabama Interagency Autism Coordinating Council and other relevant constituency groups that represent persons who have sensory impairments as described in subsection (a). The Governor, the Lieutenant Governor, and Speaker of the House of Representatives shall appoint members who reflect the racial, gender, geographic, urban/rural, and economic diversity of the state.

b. As representatives of the center's constituencies, these boards shall meet quarterly with the staff of each of the centers to provide advice on policies, priorities, and activities. Each board shall submit to the Alabama Interagency Autism Coordinating Council an annual report that evaluates the activities and accomplishments of its center during the year.

(c) To promote statewide planning and coordination, a conference shall be held annually for staff from each of the centers and representatives from each center's constituency board. The purpose of the conference shall be to facilitate coordination, networking, cross-training, and feedback among the staffs and constituency boards of the centers.

(d) Each center shall provide the following:

(1) A staff that has expertise in autism and related disabilities.

(2) Individual and direct family assistance in the home, community, and school. A center's assistance may not supplant other responsibilities of state and local agencies, and each school district shall be responsible for providing an appropriate education program for clients of a center who are school age, inclusive of preschool special education.

(3) Technical assistance and consultation services, including specific intervention and assistance for a client of the center, the family of the client, and the school district, and any other services that are appropriate.

(4) Professional training programs that include developing, providing, and evaluating preservice and inservice training in state-of-the-art practices for personnel who work with the populations served by the centers and their families.

(5) Public education programs to increase awareness of the public about autism and autistic-related disabilities.

(e) The number of regional centers shall be determined by the Alabama Interagency Autism Coordinating Council, and where possible, the centers shall be based on the campuses of state universities and colleges which provide a proposal for a center to the Alabama Interagency Autism Coordinating Council.

(f) The Alabama Interagency Autism Coordinating Council and the regional autism centers shall adopt the necessary rules to implement and administer this section.

(g) The provisions of this section shall become operative only when funds are appropriated by the Legislature through a line item appropriation.

(Act 2009-592, p. 1748, §1.)

Regional Autism Network Vision, Mission, and Values

APPENDIX B

Mission

To foster strong connections and collaborations between individuals and families directly affected by Autism Spectrum Disorder, professionals and providers, and the community to promote quality of life and enrich the fabric of society for all.

Vision

The Regional Autism Network will nurture a system of care that meets the needs of people with Autism Spectrum Disorder and their families – serving, including, and accepting them as valuable, active, and essential members of our community and state.

Values

We believe that a successful system of care will provide innovative best practices services for individuals with ASD and their families. These services should be accessible to families across the state of Alabama, provide person and family centered services, and promote meaningful public awareness and community integration and inclusion. We value a system of care that is responsive to the current sense of urgency, is accountable for providing best practice services, that includes collaborative partnerships, and offers hope to families and service providers across the state.

PERSON AND FAMILY CENTERED. *We respect and value the uniqueness of all individuals. The system of care and support that will serve those with an Autism Spectrum Disorder (ASD) is based upon the individual's distinctive strengths, abilities, interests and choices. We recognize when given the opportunity, each person can make a unique contribution to their family, community and society. They individual's needs drive their unique program.*

SENSE OF URGENCY. *Due to the overwhelming necessity for quality services and knowledgeable, reputable providers, our focus will be on the steps we can take to respond rapidly, efficiently, and effectively to the immediate and life-long needs and challenges of people living with an ASD and their families.*

PARTNERSHIPS IN ACTION. *We promote improved public awareness and understanding of those living with an ASD and advocate for public policy and funding that expands medial, therapeutic, educational, vocational, recreational, social, and residential options.*

SPIRIT OF COLLABORATION. *Cooperative partnerships will be created between those living with an ASD and their families and those agencies, organizations and professionals which serve them. These partnerships will encourage collaboration and lead to an enhanced and more efficient service delivery to their clients. We value partnerships founded on honesty, integrity and mutual respect. We will treat all interested parties with respect,*

listen to diverse views with open minds, discuss submitted public comments and foster discussions where participants can comfortably offer opposing opinions.

ACCOUNTABILITY. We will pursue innovative best practices of the highest quality for each individual to protect the safety and advance the interests of people affected by an ASD. We will promote a SMART (Specific, Measureable, Achievable, Realistic, and Time-specific) structure for service delivery. This structure will be aligned with the needs of each individual with an ASD and their family. Methods will be used to evaluate and determine the success of service delivery. Services will be adjusted as necessary to promote meaningful and successful lives for those living with an ASD.

HOPE. Although ASD can be an isolating and involved experience, we will encourage hope for the ASD community by endorsing our values on each and every service provider, agency and organization that touches them. We will also promote education for family members and those living with an ASD, so that they will be knowledgeable in what the possibilities are for their lives.

Regional Autism Network Flyer

APPENDIX C



WHO WE SERVE:

Alabama's RAN serves those who have questions, concerns, or resource needs regarding themselves, a family member, friend, client, patient, or a student with diagnosed or suspected Autism Spectrum Disorder (ASD).

WHAT WE DO:

- Professional training programs
- Technical assistance and consultation services
- Individual and direct family assistance in the home, community, and school
- Public education programs

WHO WE ARE:

Alabama's RAN is staffed by experts in the field of Autism Spectrum Disorder. Each RAN strives to connect people with ASD, their families, educators, and service providers to the information and/or services that best meet their needs.



CONTACT US:

Region I—University of Alabama in Huntsville	256-824-5700 uahran@uah.edu
Region II—University of Alabama	205-348-3131 ua-ran@ua.edu
Region III—University of South Alabama	251-410-4533 usaran@health.southalabama.edu
Region IV—Auburn University	334-844-2004 auran@auburn.edu
Region V—University of Alabama at Birmingham	205-934-1112 uabran@uab.edu

AIACC Strategic Plan

APPENDIX D

The 2014-2017 AIACC Strategic Plan¹⁰ guides the work of the AIACC. A committee is assigned to each of the five goals.

Mission Statement

The Alabama Interagency Autism Coordinating Council guides a collaborative effort to facilitate a lifelong system of care and support for persons with Autism Spectrum Disorder or associated conditions and their families, so that they may enjoy a meaningful and successful life.

Values Statement

We believe that a successful system of care will provide innovative best practices services for individuals with ASD and their families. These services should be accessible to families across the state of Alabama, provide person and family centered services, and promote meaningful public awareness and community integration and inclusion. We value a system of care that is responsive to the current sense of urgency, is accountable for providing best practice services, that includes collaborative partnerships, and offers hope to families and service providers across the state.

PERSON AND FAMILY CENTERED. We respect and value the uniqueness of all individuals. The system of care and support that will serve those with an Autism Spectrum Disorder (ASD) is based upon the individual's distinctive strengths, abilities, interests and choices. We recognize when given the opportunity, each person can make a unique contribution to their family, community and society. They individual's needs drive their unique program.

SENSE OF URGENCY. Due to the overwhelming necessity for quality services and knowledgeable, reputable providers, our focus will be on the steps we can take to respond rapidly, efficiently, and effectively to the immediate and life-long needs and challenges of people living with an ASD and their families.

PARTNERSHIPS IN ACTION. We promote improved public awareness and understanding of those living with an ASD and advocate for public policy and funding that expands medial, therapeutic, educational, vocational, recreational, social, and residential options.

SPIRIT OF COLLABORATION. Cooperative partnerships will be created between those living with an ASD and their families and those agencies, organizations and professionals which serve them. These partnerships will encourage collaboration and lead to an enhanced and more efficient service delivery to their clients. We value partnerships founded on honesty, integrity and mutual respect. We will treat all interested parties with respect, listen to diverse views with open minds, discuss submitted public comments and foster discussions where participants can comfortably offer opposing opinions.

ACCOUNTABILITY. We will pursue innovative best practices of the highest quality for each individual to protect the safety and advance the interests of people affected by an ASD. We will promote a SMART (Specific,

¹⁰ 2014-2017 Alabama Interagency Autism Coordinating Council Strategic Plan,
http://autism.alabama.gov/Documents/AIACC_Strategic_Plan.pdf

Measureable, Achievable, Realistic, and Time-specific) structure for service delivery. This structure will be aligned with the needs of each individual with an ASD and their family. Methods will be used to evaluate and determine the success of service delivery. Services will be adjusted as necessary to promote meaningful and successful lives for those living with an ASD.

HOPE. Although ASD can be an isolating and involved experience, we will encourage hope for the ASD community by endorsing our values on each and every service provider, agency and organization that touches them. We will also promote education for family members and those living with an ASD, so that they will be knowledgeable in what the possibilities are for their lives.

Goals

An integrated and overarching guiding principle of the AIACC is to cultivate an environment of understanding, communication, collaboration and consensus building among Council membership that extends to the ASD community. There are five goals of the AIACC's work, and the goals and specific activities to support them are listed below.

GOAL 1: ACCOUNTABILITY

Promote evidence-based, high quality, cost effective models and best practices that provide supports to persons with ASD and their families.

Measurement Key:

0=Not Met – no progress: no endorsements, no trainings, no meetings, no reviews no website postings, no provider updates

1=Partially Met – some progress: 1-2 endorsements, trainings, meetings, reviews, website postings and/or provider updates related to effective models and current best practices

2=Mostly Met- much progress: 3-4 endorsements, trainings, meetings, reviews, website postings, and/or provider updates

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more endorsements, trainings, meetings, reviews website postings, and/or provider updates

Objective	Completion Date	Measurement	Responsible Party
Support Universal Screening and Surveillance for ASD and Developmental Disabilities.			
Actively endorse American Academy of Pediatrics (AAP) recommendation that all primary care pediatric health care practitioners provide universal screening and surveillance for developmental delays/disabilities and ASDs.	December 2017	3 – Act Early Alabama binders with educational materials sent to pediatric practices and all Help Me Grow (HMG) coordinators for distribution; through RAN, partnering with Project ECHO to support pediatricians and healthcare practitioners	Accountability Committee
Encourage wide distribution of educational materials on	December 2017	3 – Act Early Alabama binders sent to 24 pediatric offices and	Accountability and Public

early warning signs of ASD and appropriate referrals. For example, <i>Learn the Signs. Act Early.</i> (LTSAE), Birth to Five: Watch Me Thrive.		all Help Me Grow coordinators to share with families, service providers, and pediatric offices in their regions. Materials also distributed via Children's Rehabilitation Services, home visiting programs, and early learning and outreach programs through Alabama Partnership for Children (and their Act Early Ambassador). Statewide reach through RAN, HMG, and Project ECHO.	Awareness Committees
Foster and advocate for the use of ASD-specific and developmental screenings in all appropriate early childhood settings for early identification and referral of at-risk children.	December 2017	3- RAN provides access and recommendations for screening tools in early childhood settings; AIACC and RAN support and partnership with Infant and Early Childhood Mental Health; AIACC and RAN partnership with Help Me Grow and Project LAUNCH; RAN partnership on CDC grant targeted for appropriate screenings in early childhood settings	Accountability Committee
Endorse evidence-based, best practices that people with ASD will receive in their home communities.			
Advocate for service providers to use ASD-specific best practice screening tools, interventions and services.	December 2017	3- Materials, screeners, and training provided by HMG to pediatricians local providers and families; RAN encourages regional providers and families to use best practices tools and connects them to resources; CDC grant partnering with RAN looking to support early childhood providers and settings by showing effectiveness of integrating screening tools and interventions; AIACC Diagnostics Standard of Practice developed and used to advocate for evidence based methods/tools; Project ECHO in partnership	Accountability Committee

		with RAN recommends that practices use evidence based tools.	
Promote policies and procedures that support an educated and trained multidisciplinary workforce.	December 2017	3 – RANs trainings for professionals and service providers; HMG partnership; support of Behavior Analyst Licensing Board.	Accountability Committee
Regularly review best practice and evidence-based treatment, evaluation, assessment, and diagnostic criteria.	December 2017	2 – Standards of Practice update planned for integration in next Strategic Plan over next 3 years; consistently refer and use National Autism Center and National Professional Development Center publications as reference.	Accountability and Standards of Practice Committees
Disseminate best practice and evidence-based findings (including frequent updates from national resources). For example, the Autism and Developmental Disabilities Monitoring (ADDM) Network, National Professional Development Center on Autism (NPDC), and other relevant data.	December 2017	2 – Current best practice resources distributed via trainings and e-news; Standards of Practice update planned for integration in next Strategic Plan over next 3 years; consistently refer and use National Autism Center and National Professional Development Center publications as reference; shared NAC and NPDC publications with insurance providers.	Accountability and Public Awareness Committees

GOAL 2: PUBLIC AWARENESS

Raise Public Awareness of issues and needs affecting persons with ASD and their families.

Key: 0=Not Met – no progress: no educational events, no dissemination of data and/or research findings, no support for trainings and policies for first responders, no distribution of educational materials, no promotion of transition activities, no resource directory creation or maintenance

1=Partially Met – some progress: 1-2 of the above activities to promote awareness

2=Mostly Met – much progress: 3-4 events or activities related to public awareness

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more events or activities related to public awareness for ASD

Objective	Completion Date	Measurement	Responsible Party
Support the education of service providers and the public about needs across the lifespan through strategic and collaborative partnerships.			
Advocate for educating service providers and the public about needs affecting persons with ASD and their families across the lifespan.	December 2017	3- Autism friendly by partner ASA (Regions Bank and employee training, museum in Mobile, Camp ASCCA sensory rooms and tools, businesses, sporting events, sensory movies); Public library expansion of ASD resources; exhibitor and speaking opportunities; sensory baseball games; public library autism-specific collections expansion; exhibitor opportunities; conferences	Public Awareness Committee
Coordinate and disseminate evidence-based and best practice findings and relevant data identified by the Accountability and Standards of Practice Committees.	December 2017	3- RAN provides access and recommendations for screening tools in early childhood settings; AIACC and RAN support and partnership with Infant and Early Childhood Mental Health; AIACC and RAN partnership with Help Me Grow and Project LAUNCH; RAN partnership on CDC grant targeted for appropriate screenings in early childhood settings	Public Awareness Committee
Support partnerships among AIACC, law enforcement and the Autism Society of Alabama to continue existing safety training on ASD for law enforcement and other emergency responders.	December 2017	3- Supported and shared opportunities for first responder trainings conducted statewide; Project Lifesaver expansion; Safety Net project	Public Awareness Committee
Encourage a statewide policy which requires all law enforcement and emergency responders to receive ongoing ASD training.	December 2017	2- Following legislation nationally regarding training requirements and autism. Discussions with AG's office and others regarding benefits of training. Supported and	Public Awareness Committee

		disseminated training opportunity information; supported trainings for all law enforcement.	
Support the education of service providers and the public about ASD interventions and next steps.			
Promote wide distribution of educational materials related to ASD signs, services and follow-up action steps to reduce age of first diagnosis. For example, <i>Learn the Signs. Act Early.</i>	December 2017	3- RAN provides access and recommendations for screening tools in early childhood settings; AIACC and RAN support and partnership with Infant and Early Childhood Mental Health; AIACC and RAN partnership with Help Me Grow and Project LAUNCH; RAN partnership on CDC grant targeted for appropriate screenings in early childhood settings ; Care Binder from ASA sent to families aiding in navigation of next steps; materials also distributed via Children's Rehabilitation Services, home visiting programs, and early learning and outreach programs through Alabama Partnership for Children (and their Act Early Ambassador).	Public Awareness Committee
Promote awareness of transition, vocational and post-secondary opportunities and supports for youth and adults with ASD.	December 2017	3- Roadmap to Transition developed by ASA and ADAP; RAN trainings targeting transition issues for families and providers planned for 2018; AIACC/RAN trainings for transitional age service professionals provided	Public Awareness Committee
Create and maintain an online resource directory of ASD services.			
Create online resource directory for autism services in Alabama.	June 2015	3 – Resource directory created and continually being updated	Public Awareness Committee
Maintain accurate and up-to-date data regarding available services in Alabama.	September 2015	3 – Partnering with AIACC Regional Assessment locations to complete directory - ongoing	Public Awareness Committee

GOAL 3: FUNDING

Identify and promote opportunities for diversified public and private partnerships that expand needed funding.

Key: 0= Not Met – no progress: no strategies to increase insurance coverage, opportunities for diagnostic evaluations, waivers and support services and/or state spending and support

1=Partially Met – some progress: 1-2 opportunities or strategies (as described above) identified and/or promoted

2= Mostly Met – much progress: 3-4 opportunities or strategies identified and/or promoted

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more opportunities or strategies for funding expansion were identified and/or promoted

Objective	Completion Date	Measurement	Responsible Party
Utilize multiple strategies to focus on the various sources of Insurance (private, public, employer funded, privately funded) to increase appropriate levels of coverage and reimbursements for ASD specific treatments such as Applied Behavior Analysis therapy, occupational therapy, speech-language, and other related services.			
Advocate for parity in insurance coverage for comprehensive array of services for Alabamians with ASD.	December 2017	3 – Reviewed and helped provide data for anticipated cost of services and billing code resources; advocacy from AIACC members at Autism Legislative Day; 2017 autism insurance legislation passed that impacts private health benefit plans, as well as SEHIB, PEEHIP, Alabama Medicaid (EPSDT), and ALL Kids.	Funding and Finance Committee
Support a national platform that 3rd party insurance should cover screening, evaluations, and therapies as part of basic plans.	December 2017	3 – Expressed need of coverage for ABA therapy in all plans; supported changes in 2017 autism legislation.	Funding and Finance Committee
Explore opportunities to consult with insurers regarding outcome metrics, quality indicators and utilization indicators of service effectiveness.	December 2017	2- Developmental screenings in RCO outcome measures in 2015; ongoing discussions relating to 2017 autism legislation and various health benefit plans.	Funding & Finance and Standards of Practice Committees
Support access to diagnostic evaluations.			

Identify and address barriers to diagnostic evaluations.	December 2017	2 – insurance barriers; number of qualified service providers; geographic access; waiting lists for diagnostics can be one year or more	Funding and Finance and Accessibility Workgroups
Examine and capitalize on existing opportunities in the Medicaid and Education fields (such as the mental health pilots in the Montgomery schools). (Potential Partners: Alabama Arise and Disability Leadership Coalition).	December 2017	2- AIACC members part of Alabama Disability Leadership Coalition; Mental Health Goal Group Membership part of Bold Goals initiative; barrier identified that Autism not currently classified as Mental Health.	Funding and Finance Committee
Advocate for expanded and improved waivers and supports for persons with ASD.			
Engage with Alabama Medicaid to advocate for the healthcare needs of individuals with ASD and Developmental Disabilities (Potential Partner: Medicaid Regional Care Organizations).	December 2017	3- Meetings with AL Medicaid and national information shared; ABA therapy discussion ongoing; settlement negotiations expected to provide further engagement opportunities with Alabama Medicaid; Developmental Disabilities a continued area of focus	Funding and Finance Committee
Explore options for improved coverage for persons with ASD in the current and future Medicaid program. For example, an autism-specific waiver to include individuals without Intellectual Disability.	December 2017	3- Met with AMA to discuss EPSDT and waiver issues related to ABA therapy; discussion ongoing; explored new waiver requirements and emphasis on use of EPSDT; need for Developmental Disabilities waiver still identified as a priority need	Funding and Finance Committee
Collaborate with state agencies to identify new models for the use of waiver services for the ASD population. (Potential Partners: Alabama Department of Mental Health, Alabama Department of Public Health, Alabama Department of Rehabilitation Services).	December 2017	3- Met with DMH re: Autism Waiver; exploring use/benefit of DD waiver; ASD-specific waiver not preferred anymore by CMS, but rather the DD waiver; discussions regarding new models ongoing	Funding and Finance Committee

Advocate for state spending and support for those with ASD.			
Determine funding needs to achieve goals of the AIACC, including the Regional Autism Networks, and recommend ways to include ASD in budget considerations of the Executive and Legislative Branches for publicly funded services.	December 2017	3 – Budget proposal for RAN submitted; RAN funding for all 5 regions included in legislative ETF budget; ASD funding being considered in Medicaid; expanded funding needed for RAN to create option for full time staff and other resources	Funding and Finance Committee
Advocate for ASD diagnosis to be included in Medicaid Regional Care Organizations.	December 2017	2- Disabilities Leadership Coalition representatives on RCOs; recommendations made; RCOs changed to a health home model	Funding and Finance Committee
Advocate for more coordination and sharing of human and financial resources to address the issues of people with ASD across the lifespan.	December 2017	3- Collaboration discussions held during committee/council meetings; RAN facilitates more coordination; education during legislative day	Funding and Finance Committee
Advocate for an autism database that may be used to know how many in Alabama are affected by ASD for service and budget planning purposes.	December 2017	2 – Current estimates on number affected by ASD in Alabama is based on 1:68 prevalence rate applied to census data; requests for data made; RAN data or Autism ID card might be beginnings of database	Funding and Finance Committee
Support funding of Regional Autism Networks.			
Perform cost analysis to determine cost per Regional Autism Network.	February 2015	3- Study completed	Funding & Finance Committee
Advocate for a line item in the Alabama budget for at least two Regional Autism Network locations, with more to be added in subsequent years.	December 2015	2 – Five pilot locations proposed; Request made in 2015 for \$500k but request was denied. In 2016, 3 RANs were funded at \$75k each. In 2017, additional 2 RANs funded, making project statewide. Expanded funding still needed.	Funding & Finance Committee

Develop funding flow recommendations for the Regional Autism Networks Committee to consider during Request for Proposal development.	May 2015	3 – RANs are funded through DMH and the AIACC. Funds are distributed quarterly.	Funding & Finance and Regional Networks Committees
Determine reporting requirements for each Regional Autism Network in regard to funding.	May 2015	3 – Quarterly reports are collected from participating RANs in conjunction with the payment periods. Revised yearly.	Funding & Finance Committee

GOAL 4: ACCESSIBILITY

Advocate for increased choice among and access to quality services and supports for people with ASD and their families.

Key: 0=Not Met – no progress: no collaborations with state partners to communicate services and/or transition issues, no supports for a coordinated system of care or more flexible eligibility criteria

1=Partially Met- some progress: 1-2 collaborations or opportunities for supporting increased access and choice

2=Mostly Met – much progress: 3-4 collaborations or support opportunities

3=Completely Met/Sustaining – totally satisfactory progress: 5 or more collaborations or support opportunities for increasing access and choice of services and supports

Objective	Completion Date	Measurement	Responsible Party
Advocate for increased choice among and access to quality services and supports for persons and families within ASD community-based systems of care.			
Collaborate with state partners to identify and communicate local and state services available to children, youth and adults.	December 2017	3 – AAPN and ASA putting together comprehensive list of public and private providers; discussions ongoing with state partners providing related services; partnership with public and private providers to communicate services; presentation developed and shared to families and providers.	Accessibility and Public Awareness Committees
Advocate for increased access to diagnostic evaluations,	December 2017	3 – Access to services related to insurance/funding, geographic, and wait list are persistent	Accessibility Committee

treatment, and supports across the lifespan.		barriers. Trainings and referrals to help navigate are ongoing through partners and RAN. Partner organizations also providing advocacy for insurance access to treatment, in particular. Insurance changes enacted due to advocacy efforts from partner groups.	
Encourage publicly-funded service systems to allow people with ASD to access services under more flexible eligibility criteria. For example, account for social-emotional, adaptive, and functional deficits as well as communication, academic and cognitive.	December 2017	3- Met with ADRS to discuss services and available possible collaborations to improve service delivery to people with ASD. Received approval for Autism Liaison for Birmingham office. Early Intervention is working on their State Systemic Improvement Plan regarding social/emotional needs of children they serve. Early Infant Mental Health Consultation development ongoing through Project LAUNCH and other partners, also addressing social/emotional needs (not ASD-specific, but certainly relevant). Alabama Medicaid considering expansion of eligibility and services.	Accessibility Committee
Encourage and support a coordinated system of intervention and care for transition age students that include the person with ASD, parents, mentors and support agencies and that addresses transition issues, job training and coaching, college support, daily living skills, communication and social skills.	December 2017	3- WIOA plan being implemented and supports transition age students; partner agencies working with Vocational Rehabilitation in implementation of WIOA plan; RAN training for transition issues on the calendar for 2018	Accessibility Committee
Collaborate with Alabama State Department of Education's Autism team and others to identify youth and	December 2017	2 – Pilot transition program currently ongoing through partner organization in Montgomery, Autauga, and	Accessibility Committee

young adults transitioning from school in order to address training and work issues earlier in the youth's schooling.		Elmore counties; WIOA being implemented statewide, allowing earlier access to Vocational Rehabilitation services at age 14; continued partnership with ALSDE Autism Team.	
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GOAL 5: REGIONAL NETWORKS

Develop and coordinate necessary resources that allow for the creation of Regional Autism Networks. (See Appendix A for legislation outlining requirements of Regional Autism Networks.)

Regional Networks/System Support - Phase 1 – (Initial steps: 1-Establish budget (cost analysis) for budget request to legislature, 2-Identify process and develop RFP, 3-Support submission of budget request to legislature, 4-Identify contact in each region submitting response to RFP, 5-Develop annual reporting requirements for Regional Autism Networks)

Key: 0=Not Met-No initial steps taken

1=Partially Met-1-2 initial steps completed or initiated

2=Mostly Met – 3-4 initial steps completed or initiated

3=Completely Met/Sustaining – totally satisfactory progress: All 5 initial steps completed or initiated to be completed within an appropriate time frame.

Objective	Completion Date	Measurement	Responsible Party
Advocate for, promote, and encourage the establishment of four to six Regional Autism Networks in accordance with Act 2009-592.			
Support the cost analysis conducted by the Funding and Finance Committee to determine the amount of a budget request to state legislature.	December 2014	3- Budget proposal is complete and used as a guide when planning for Regional Networks' current and future funding needs.	Regional Network and Funding & Finance Committees
Identify process and develop Request for Proposal.	March 2015	3 – Process developed – budget proposals received; desired sites identified (UAB, USA, AU, UA, UAH)	Regional Network Committee
Support submission of budget request to legislature.	March 2015	3- Request made in 2015 unsuccessfully; support for 3 RAN sites provided in 2016. Remaining 2 sites funded in	Regional Network and Funding and Finance Committees

		2017. Expanded funding still needed.	
Identify contact in each region submitting response to Request for Proposal.	October 2015	3- Regional contacts identified	Regional Network Committee
Develop annual reporting requirements for Regional Autism Networks.	October 2015	3 – Quarterly reports being collected and annual report due at end of fiscal year.	Regional Network Committee
Share information about Regional Autism Networks as it becomes available.	Ongoing (pending allocation of funding for Regional Autism Networks)	3 – RANs announced presence via email, social media, partner organizations, exhibits, and outreach.	Regional Network Committee
Assure public awareness/education campaign is in place in conjunction with the development of the regional networks	Ongoing (pending allocation of funding for Regional Autism Networks)	3 – Public awareness campaign developed, conducted, and ongoing.	Regional Network Committee
Support an increase the number of qualified and competent ASD trained professionals, personnel, and providers.			
Support programs and policies designed to increase the number of qualified and competent ASD trained professionals, personnel, and providers.	December 2017	3 – Trainings being conducted and planned through the RAN for service providers, educators, and family members and people with ASD (to know what aspects of services to prioritize and identify). Planning for trainings for healthcare providers being planned for 2018.	Regional Network Committee
Encourage university officials to increase university-based degree and certificate programs that provide ASD specific training	December 2017	3 – Autism specific university degree and certificate programs have been expanded. Meeting held with university representatives and providers to discuss ways to collaborate and expand training opportunities.	Regional Network Committee

Alabama Interagency Autism Coordinating Council

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